Evidence Submitted to
The Law Commission 2015
Consultation on the
Law on Mental Capacity
and Deprivation of Liberty

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University of York
Also representing Advance Decisions Assistance (ADA)
A. About us

We are responding in a dual capacity: as academics with research expertise in the area of advance decisions, and as the co-founders of the charity Advance Decisions Assistance (ADA), established in June 2015.

Celia Kitzinger

Celia Kitzinger PhD, CPsychol, FBPsS is a Professor in the Sociology Department at the University of York, a Chartered Psychologist, and Co-Director of the Coma and Disorders of Consciousness Research Centre an interdisciplinary group of scholars across the Universities of York and Cardiff carrying out research on the historical, sociological, ethical, legal and economic aspects of coma, the vegetative state and the minimally conscious state. This research, funded largely by the Wellcome Trust and by the Economic and Social Research Council (ESRC), has won prizes for outstanding social impact (from the ESRC) and for patient information on ethical issues (from the British Medical Association). Celia was also Principal Investigator in an interdisciplinary research seminar series on “Advance Decisions: Informing Implementation Strategies through Interdisciplinary and Cross-national Dialogue” (funded by the ESRC). She has lectured widely on advance decisions, including training for social and health care professionals, and in 2016 will be teaching Continuing Professional Development courses approved by the British Psychological Society (jointly with Sue Wilkinson).

Sue Wilkinson

Sue Wilkinson PhD, CPsychol, FBPsS is an Honorary Professor in the Sociology Department at the University of York, and a Chartered Psychologist. She is a specialist in healthcare communication, particularly around end-of-life issues. She conducts action research projects with charities, focused on service evaluation and improvement, particularly in relation to telephone helplines. She recently evaluated Compass in Dying’s End-of-Life Rights Information Line, and is currently evaluating Dementia UK’s Admiral Nursing Direct Helpline. She has lectured widely on advance decisions, including training for social and health care professionals, and in 2016 will be teaching Continuing Professional Development courses approved by the British Psychological Society (jointly with Celia Kitzinger).

Advance Decisions Assistance (ADA) is a charity which:

- Raises awareness of advance decisions, and provides direct one-to-one support to help people write (or review) them, and advises people on related issues (such as the relationship between advance decisions and other legal documents such as Powers of Attorney).
- Provides training for GPs, other healthcare practitioners, and other relevant professionals
- Conducts and supports research into advance decisions
B. Our Focus in this feedback

Our feedback is limited to your concern with advance decisions to refuse treatment, and in particular to your wish “to explore ways in which advance decision-making, in general, could become more central to health and social care” (13.34)

13.34 ... For example, some stakeholders have suggested that practitioners should be required to discuss the options with patients and service users, while others have suggested the use of statutory forms for this purpose. There may also be a need to require decision-makers to record in the care plan that a person has made a form of advance decision.

We welcome further views on whether legal solutions would be appropriate and useful in this context.

C. Summary of Feedback

Key Points

1. No legal solutions are likely to be effective without information/education about Advance Decisions (ADs) for the general public and (most importantly) for healthcare practitioners and other relevant professionals.

2. We support, in principle, a legal requirement for practitioners to discuss advance decisions to refuse treatment with patients/service users – but further consultation is needed as to which practitioners, how they will be trained, and how this can be financed.

3. We support, in principle, a legal requirement for proper record-keeping concerning advance decisions. Further consultation is needed to determine how this should be done, especially in relation to DNACPR decisions. We favour a national repository along the lines of the NHS Organ Donor Register www.nhs.uk/Conditions/Organ-donation/Pages/Donationprocess.aspx. We would like the Law Commission to recommend for consideration by Parliament the creation of a national repository so that advance decisions are available when needed.

4. In order to underscore the legal basis of advance decisions to refuse treatment and to ensure that health care professionals comply with them in future, we need a test case for tortious battery where treatment has been given contrary to a valid and applicable AD.

5. We are cautious about the development of statutory forms for ADs, but believe that the creation of a simple statutory ‘opt out’ form for people who want to refuse life-prolonging treatment if they were PVS/MCS is an urgent and important task.

6. We advise against the use of solicitors to assist the public in drawing up advance decisions to refuse treatment – but recognising that members of the public are likely to ask for help from solicitors, we recommend the creation of more adequate training materials for solicitors. We support the use of solicitors in helping with LPAs for Health & Welfare but note that solicitors also require further training about the relationship between ADs and LPAs.

7. We advise revisions to the form for Lasting Power of Attorney (Health & Welfare) to make clear if an AD is also in place and is intended to remain valid alongside the LPA.

8. We ask the Law Commission to recommend reform of Practice Direction 9e to address the legal anomaly between PD9e and the Mental Capacity Act 2005.
D. Detailed Feedback

No legal solutions are likely to be effective without information/education about ADs for the general public and (most importantly) for healthcare practitioners and other relevant professionals.

In order to promote uptake of ADs such that they become more central to health and social care we urgently recommend:

- a public information campaign (eg government promotion including TV, other digital and print advertising, information leaflets in GP surgeries and other healthcare contexts)
- on-going training and support for healthcare practitioners and other relevant professionals – who currently show very low awareness about either the existence of ADs or their operation.

The very low uptake of ADs (around 4% of the general population) is an inevitable outcome of lack of knowledge that this possibility exists. This compares poorly to countries where information about ADs (or their equivalent) is widely disseminated and uptake is somewhat around a third of all adults over 18 (varying from 26% to about 33% depending on the study).

There is also, in the UK, a common misperception concerning the rights of next-of-kin. Even academic and some practitioner audiences are surprised that next-of-kin cannot lawfully make decisions for another adult. This erroneous belief is one reason why people either do not write ADs (ie “my family knows what I want”) or do not appoint an LPA for Health & Welfare (since they believe the spouse or adult son/daughter who they would wish to make decisions already has decision-making power).

In the training we have done via ADA, we have encountered the following problems:

- There is widespread lack of awareness among GPs.
- ADs are often conflated with advance care planning more generally, or with LPAs.
- Many GPs do not understand the distinction between prospective autonomy and best interests decision-making, believing that a valid and applicable AD is just one more constituent of a best interests decision. When informed otherwise, many are concerned about “unwise decisions” and believe that once a person has lost capacity (if not before) they, as health care professionals, can override an “unwise decision” with a best interests decision.

There is also a great deal of anxiety about how to engage with patients’ relatives when relatives are demanding treatment that has been refused in an AD. (As one doctor said: “The patient is dying and unconscious and isn’t going to lodge a complaint about me or sue – the angry family member just might.”)

There are also problems of understanding relating to the presumption of capacity at the point at which people decide they want to write ADs. We have found that GPs routinely express concern about the decision-making capacity of anyone with an impairment of, or a disturbance in, the functioning of, the mind or brain (without ever engaging with the question of whether or not they can nonetheless understand, retain and weigh the information relevant to their AD decisions). We have worked with people who have just received dementia diagnoses, people with mild brain injuries, and people with mental health problems – especially depression – who report that their GPs (or other health care professionals) have told them they cannot make ADs on the grounds that they lack mental capacity to do so. As far as we know, no evidence has been offered in support of this opinion, and in not one case has the disabled person been offered support and assistance with decision-making (as required by the Mental Capacity Act 2005) to help them access their right to make an advance decision. In our own view, all of

1 Documented in Wilkinson, S. (2016, in press) Barriers to making an Advance Decision to refuse treatment: An analysis of calls to an end-of-life rights helpline
these people who we worked with in fact had the capacity to make a legally binding advance decision (with our support). While some GPs acknowledge that capacity assessment is part of their everyday job (i.e. in establishing consent to treatment) many express concern about their role in assessing capacity for the purpose of writing advance decisions. When someone has borderline or fluctuating capacity, or when their capacity might be in doubt due to an impairment or disturbance of their mind or brain, many charities (including ADA) advise them to ask for a signature from their GPs on their AD form, confirming that (in the GP’s view) they have the capacity to make the decisions contained in the AD at that time. Some GPs are reluctant to do this – not because they doubt the person’s capacity, but because they apparently doubt their own ability to assess the patient’s capacity in this situation. (Others apparently refuse for other reasons, e.g. according to some members of the public, GPs have refused signatures because they do not want to be associated with “assisted dying”.)

The relationship between advance decisions to refuse treatment and the Mental Health Act is also not well understood. It would be helpful for the Law Commission to develop FAQs on this topic. We have focused here on the need for training for GPs because this is where our expertise lies – but we have also done a limited amount of training with neurosurgeons, care home staff, and Independent Mental Capacity Advocates (IMCAs), and will shortly begin training psychologists. Our general observation that all healthcare practitioners (as well as many other professionals) require more training about advance decisions to refuse treatment is informed also by our work with these groups. Only with sufficient training and education of practitioners can the pervasive and systemic problems with advance decisions be overcome.

As just one example of how the current problems are embedded in policy and practice, please have a look at the NHS Devon Treatment Escalation Plan (TEP) and Resuscitation Decision Record www.devontep.co.uk/wp-content/uploads/2012/03/V10_TEP_FINAL_INFO_ONLY.pdf. Although there are many excellent features of this form and the underlying process of advance care planning it represents, it embodies a misconception about the role of ADs: the flow chart on the second page instructs practitioners that if a person is found to lack capacity but has an AD then the healthcare practitioner should “Incorporate into TEP form or Best Interests Decision”. Obviously a valid and applicable AD should not be incorporated into a best interests decision – it obviates the need for a best interests decision. The need for training is clear when even NHS documentation embodies these kinds of misconceptions.

“" A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.”

(s 1(3) Mental Capacity Act 2005)
A suggestion is made in 13.34 that practitioners should be required by law to discuss options with patients/service users.

Which practitioners? There is currently no practitioner group with the knowledge and skills base to do this adequately with respect to advance decisions to refuse treatment. In addition to GPs and practice nurses, relevant practitioners could include specialist consultants, dementia care nurses, surgeons before surgery as part of the consenting process, community nurses, social workers, IMCAs, and psychologists/counsellors. These groups often have currently low awareness of ADs and would need training in order to be able to do this.

This requirement could not work without further education of healthcare professionals (see 1 above). Many health care professionals are uncomfortable with the legal aspects of ADs and do not feel competent to assist someone in producing a legally-binding AD. Charities that assist people with ADs report having been advised to turn to solicitors.

Should there be a “conscientious objection” clause in any legal requirement to discuss ADs? A range of practitioners (GPs, palliative care nurses doing advance care planning, etc) can – and do – discuss future care options in general, but a legally binding advance decision to refuse treatment is very rarely among the options discussed (much less promoted or enabled). Many health care practitioners believe a legally-binding treatment refusal to be unnecessary, or even to get in the way of good end-of-life care, and do not offer ADs as an option for that reason. Some believe ADs to be tantamount to “assisted suicide” and refuse to discuss them, thereby depriving the person of a choice that should be available to them.

The proposed requirement for practitioners to discuss advance decisions to refuse treatment with patients/service users would also be very costly in terms of the amount of time that would need to be invested in it. In our experience with ADA (to date, we have helped 200+ people to write advance decisions), assisting a person with writing an AD takes about an hour (40 minutes for the initial discussion and production of a draft, and then a 20 minute follow up a couple of weeks later after the person has had the opportunity to reflect on their decisions, discuss them with family/friends, raise additional questions etc). Can we identify a practitioner group that has this amount of time available? (GPs and practice nurses certainly don’t.) Would additional funding – and/or incentivization – help? Note that from 2016 the USA Centers for Medicare and Medicaid Services are revising their payment rules to provide financial cover for “patient- and family-centred care for seniors and other Medicare beneficiaries by enabling them to discuss advance care planning with their providers”:

We support, in principle, a legal requirement for practitioners to discuss advance decisions to refuse treatment with patients/service users – but further consultation is needed as to which practitioners, how they will be trained and how this can be financed.


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One of the biggest anxieties expressed by people who have written ADs (and a disincentive to those considering doing so) is that especially in an emergency situation – nobody will know either that they have an AD or where their AD is, let alone what treatments they are actually refusing. Ambulance services tell us that it is the responsibly of the patient to bring the AD to the attention of paramedics and first responders, but there is no clear and systematic way of doing this (and obviously, at the time it is actually most needed, the patient is unlikely to be in a position to do so).

The suggestion (in 13.34) that “there may also be a need to require decision-makers to record in the care plan that a person has made a form of advance decision” is one we support, but it does not go far enough. It would apply only to people who have a “care plan” – most of the people who contact ADA for assistance with writing their ADs do not have a terminal illness and/or are not on an end-of-life care pathway; indeed, many are perfectly healthy. It is a key concern of many people with ADs that nobody will know that they have one at the point at which it will matter – and the most we can do at present is advise them to get their AD scanned into their GP records, and ensure that copies are lodged with other healthcare providers, family members and friends. (One colleague tells us, however, that an ambulance crew refused to honour an AD because they were presented with a photocopy rather than an original.)

We also advise clients to adopt one or more ad hoc solutions such as MedicAlert or SOS Talisman jewellery, or the Lions “message in a bottle” scheme. Some people we have met have resorted to a tattoo to alert healthcare practitioners to their wishes. Tattoos are unlikely to fulfil the requirements for a valid advance decision (the ones we have seen are not signed, dated or witnessed) but they are evidence of the desperation some people feel about having their treatment
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refusals respected. A video of one man talking about his tattoo is available on the ADA website here: www.adassistance.org.uk/hints-and-tips/

We are particularly concerned about how ADs intersect with DNACPR decisions. This is often raised by ADA clients who are refusing CPR as part of their AD and wonder how anyone will know about this if they were to collapse outside the home. At present there is no clear answer to this question. We do advise clients to discuss this with their GP, and to ask to be placed on their local Ambulance Trust Register for DNACPR. There are real problems with this. First, GPs may not oblige, especially if the patient does not have a terminal illness. Second, these are local registers and may not be accessible if the person collapses outside the area covered by their local Ambulance Trust. Third it appears that many Ambulance Trusts rely on a computer-based clinical patient management system (Adatra) which readily permits a DNACPR decision to be logged only if the patient has a terminal illness: so it may not actually be possible to log the DNACPR decision for a patient whose AD refuses CPR but who is not terminally ill. This means that the legal right to refuse CPR is being denied – especially to patients without life-limiting illnesses – because of technical problems in the way that forms and computer systems are designed. This is not in accordance with either the spirit or the intention of the Mental Capacity Act 2005. (Note: The Resuscitation Council is working on new forms which we hope will go some way to resolving some of these problems. https://www.resus.org.uk/statements/emergency-care-and-cpr-decision-making/#update)

In order to underscore the legal basis of advance decisions to refuse treatment and to ensure that health care professionals comply with them in future, we need a test case for tortious battery where treatment has been given contrary to a valid and applicable AD.

In our work assisting ordinary members of the public to write ADs and in training professionals about ADs, we experience a real mismatch between these two client groups. Members of the public seeking assistance from ADA are usually not afraid of death but are frightened about the dying process. Many have witnessed poor quality of life/‘bad deaths’ e.g. of a relative through end-stage dementia, motor neurone disease or catastrophic brain injury. (For video clips of people discussing the impact of catastrophic brain injury see: www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/reflections-own-end-life-wishes.) ADA clients are typically committed to “quality” – rather than “quantity” – of life, and are very keen to avoid treatments that will prolong the dying process. They are concerned to ensure that that their treatment refusals will be respected. We deal with many questions about how doctors will know about their ADs, whether or not they are definitely legally-binding, how to close any loopholes that would mean they receive treatment against their wishes, and (sometimes) how to ensure that family members are not given decision-making rights that would result in unwanted treatments being administered (“because my children aren’t ready to let me go”). As far as possible we work with these clients to shore up the validity and likely future applicability of their AD against possible challenges.

By contrast the approach of professionals for whom we provide training is often quite different (at least when speaking as practitioners, rather than as people who might want an AD for themselves). Doctors and solicitors we work with regularly say that their first move when confronted with an AD is to question its legal status. Solicitors for CCGs and Trusts have told us that they would “err on the side of caution” – by which they mean recommending that life-prolonging treatment is administered against the person’s stated AD while further investigation as to the validity of the instrument is undertaken (or, in some cases, it is referred to court). Although there is a presumption of capacity embedded into the Mental Capacity Act 2005, both doctors and solicitors tell us that an advance decision immediately raises for them the question of the capacity of the person at the time that they wrote it. The following comments have been made in training sessions by practising GPs:

- I’d need to see a formal capacity statement testifying that the person had capacity at the time they wrote the AD. I think without that I’d have to go ahead and treat.

If the person has dementia now, how do I know they didn’t write it when they were depressed about their diagnosis or already losing capacity?

I’d be very concerned, if an AD came to light for any of my patients, that they had been leant on by family members who are keen to inherit from Granny. Vulnerable older people can be very suggestible.

I’d take account of an advance decision but actually my duty of care means I have to do what’s best for the patient, especially once they’ve lost capacity.

We also have personal experience of the way in which the legal status of an advance decision that conformed to all the requirements of the Mental Capacity Act 2005 was challenged by professional carers. Celia’s mother died in April 2015. Her advance decision was challenged by health professionals on the basis that it was dated 2012, two and a half years earlier, and the patient “might have changed her mind since then”. It was also challenged on the basis that the witness to the signature was one of the patient’s daughters, which was deemed “illegal” because a family member “might stand to benefit from the patient’s death”.

It is clearly apparent that, for health care professionals (and some CCG and Trust solicitors) anxiety about the consequences of complying with an advance decision greatly outweighs anxiety about the consequences of administering treatment that has been refused. We believe that lawyers need to send out a clear signal to reverse this situation. The right of a capacitous patient to refuse treatment was promoted and enhanced by the publicity following the landmark case of Re B (Adult: Refusal of Medical Treatment) [2002] 2 All England Reports 449. A similar case is needed to ensure the right of a non-capacitous patient with an AD that specifically refuses the treatment that has been administered.

Recent court hearings have upheld advance decisions even when they have had technical flaws (like the ‘valid until’ date in X Primary Care Trust v XB [2012] EWHC 1390 (Fam)). Respect for the prospective autonomy of ordinary members of the public means that health care professionals need at least to be willing to act in accordance with advance decisions that meet the legal requirements of the Mental Capacity Act 2005. A test case showing that not doing so can be as legally damaging to a CCG/Trust as so doing would give health care professionals the confidence they need to accept valid and applicable treatment refusals in ADs.
There are already a number of templates for writing advance decisions available on the internet – mostly provided by charities. Some of these templates are generic – for example, those available from:

- Compassion in Dying: [www.compassionindying.org.uk/library/advance-decision-pack](http://www.compassionindying.org.uk/library/advance-decision-pack)
- Other templates are designed to be condition-specific (to a greater or lesser degree) – for example, those available from:

Along with colleagues from law, medicine, ethics and nursing, we reviewed many of these templates as part of the ESRC seminar series on “Advance Decisions: Informing Implementation Strategies through Interdisciplinary and Cross-national Dialogue”, and also compared them with some of those available in the USA. There were none that we considered wholly satisfactory for the range of potential people who might wish to complete them: which might include healthy 20 year olds, the frail elderly, people with long-term chronic conditions, people with life-limiting conditions, people with fluctuating or uncertain capacity, and those with strong religious values.

Based on the templates currently available for ADs, we believe that a statutory AD form would have both advantages and disadvantages.

One key advantage would be to provide a framework for thinking about what to include in an AD. People seeking help with ADs regularly tell us that they “don’t know all the treatments they might need to consider” or “can’t imagine the range of things which might happen in the future”. A list presented in tick-box format provides a menu of options. However, this is also a disadvantage, insofar as it discourages people from thinking outside/beyond the options provided, and so risks failing accurately to represent an individual’s wishes (for example, the omission of the ‘minimally conscious state’ from many template forms – see section 6 below). Additionally, many people feel that although the medical profession can advise them about medical matters and the risks and benefits associated with different treatments, they are the experts on their own values and beliefs, their attitudes toward life and what makes it worthwhile to them, and their views about death, disability and risk. These are the very issues typically not reflected on existing templates, and – based on our experience of trying to incorporate them within a standard format – it is actually very difficult to get this right.

Existing templates are of variable quality. Some are flawed by key omissions and/or inaccuracies and in worst case scenarios people may be ill-advised or misled by using them (see X Primary Care Trust v XB [2012] EWHC 1390 (Fam)) – which came to court because the date of signing was conflated with a ‘valid until’ date, so the AD was not technically valid).

The better templates – eg that of the charity Compassion in Dying, on which we advised the charity as expert consultants over various iterations – are now very extensive, and hence very ‘accurate’/‘well explained’. But ADA clients tell us they are “daunted” by the number of questions on the Compassion in Dying form and “overwhelmed” by the sheer volume of information that they need to process in reading the accompanying guidance notes.

Further, many older people – the main client group currently completing ADs – are also daunted by the prospect of completing a form online; and some do not have the IT skills needed even to access an online form or scroll down pages, and so (in cases where paper versions are not also available) these people are effectively excluded from being able

"Up to 16,000 patients in a permanent vegetative state are currently being given life-sustaining treatment in the UK today."

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We are cautious about the development of statutory forms for ADs, but believe that the creation of a simple statutory ‘opt out’ form for people who want to refuse life-prolonging treatment if they were PVS/MCS is an urgent and important task.

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We advise against the use of solicitors to assist the public in drawing up advance decisions to refuse treatment – but recognising that members of the public are likely to ask for help from solicitors we recommend the creation of more adequate training materials for solicitors. We support the use of solicitors in helping with LPAs for Health & Welfare but note that solicitors also require further training about the relationship between ADs and LPAs.

Clearly it was not the intention of the Mental Capacity Act 2005 to require the involvement of solicitors in creating ADs, but there is a common public misperception that because an AD is a legally-binding document, it requires a solicitor to draw one up. This misconception is unhelpful because:

- It deters medical practitioners (including practitioners assisting with advance care planning in end-of-life settings) from offering assistance with ADs.
- The expense involved in consulting a solicitor deters members of the public from creating ADs.
- Our evidence is that solicitors are not very good at producing ADs for clients.

As part of our work with ADA, dozens of clients have brought us, for review, ADs drawn up for them by solicitors. Unlike some other ADs we have seen these are correctly drawn up in the sense that they fulfil the legal requirements for a valid instrument as laid out by the Mental Capacity Act 2005. However, we are very concerned about the quality of these ADs for two other reasons:

(i) ADs drawn up by solicitors often do not reflect the client’s own wishes

In one case, a client had signed a document refusing treatment that she did not in fact wish to refuse. Her AD refused “all medical treatments” under specified circumstances. In discussion with us it became clear that she had not realised that clinically-assisted nutrition and hydration (CANH) is a medical treatment and that by refusing “all medical treatments” she had refused CANH. Although she subsequently (after discussion about the pros and cons of CANH and palliative care options) decided she did want to refuse CANH, she was initially quite distressed to find she had inadvertently signed a document refusing CANH, counter to her intention.

Much more commonly, solicitors’ clients have signed a document that does NOT refuse all the treatment that they in fact wished to refuse or does not refuse treatment under the circumstances under which they had intended to do so. For example, several clients have shown us ADs drawn up by solicitors that refuse life-sustaining treatments in the event of their being in a Permanent Vegetative State (PVS). In no such cases have these clients understood...
that a Permanent VS cannot be diagnosed until (at a minimum) 6 months after an anoxic brain injury and 12 months after a traumatic brain injury. In no such case has the client actually wanted to be maintained in a vegetative state for as long as 6 months. We helped clients rewrite these ADs to reflect their wishes (eg to be maintained in a vegetative state for only 4 weeks, or 12 weeks, etc). Similarly not one of the ADs that we have seen drawn up by solicitors included treatment refusal in the event of the client being in a Minimally Conscious State (MCS) – despite some having been drafted after the recent high-profile case of W v M and others [2011] EWHC 2443 (Fam). To date, every ADA client, when informed about this option, has elected to add treatment refusal in the event of MCS.

(ii) ADs drawn up by solicitors are written in language only a lawyer is likely to understand and be persuaded by: this means they are likely to be ineffective in practice at the point at which treatment refusal matters. ADs written by solicitors often use complex and defensive legal language, mired in complex conditionals with numbered clauses and sub-clauses nested within each elaborate and convoluted sentence. The people who need to be able to read, understand, and act on an advance decision are – in the first instance – not lawyers. They are first responders at emergencies, paramedics, intensivists, doctors in hospices etc. ADs need to be written in simple, direct, straightforward language that someone can read and make sense of before deciding whether or not to give CPR or attach a ventilator. They also need to be persuasive to paramedics, intensivists, etc. so that these practitioners withhold or withdraw unwanted treatment right away. An AD that goes to a lawyer – or worse, a court – for a legal opinion before implementation has already failed, since the client is likely to have been given unwanted treatment in the interim. If solicitors are to write ADs for people – and frankly we do not think they are the right professional group to be doing this – then they need to be able to produce a document that is not only legally binding and reflects the client’s wishes (see above) but also is effective in the sense of leading to withdrawal/withholding of unwanted treatment in practice.

Two examples give a sense of the scope of the problem:

- Paramedics regularly tell us that they need bullet points on the front page of an AD saying “Not for CPR” or “No artificial ventilation” – they don’t have time in these circumstances to read through a three page legal document.

- One intensivist told us he would not comply with an AD unless he was shown because it had a “bullying” tone and didn’t include the words “please” and “thank you”. Another said that he would be more likely to comply with an AD if it acknowledged his own moral distress and disempowerment at the fact that he was being refused the opportunity to use his life-sustaining skills. He responded well when we suggested adding to ADs some sentence such as: “I am sorry for any pain you might feel at allowing my death and thank you from the bottom of my heart for respecting my deeply-held wishes as expressed in this document.” To be effective in practice an AD may need to do more than is legally required for a valid AD.

Since members of the public are likely to continue to consult solicitors about ADs, we recommend the development of more adequate training materials for solicitors to enable them better to understand and reflect the personal wishes of clients, and also better to understand the vagaries of the situations in which ADs are read and acted upon (or not), i.e. by paramedics, in emergency rooms, etc.

Finally, we want to draw attention to our concern with the role of solicitors in helping people who already have ADs with applications to appoint someone with Lasting Power of Attorney for Health & Welfare. We believe that solicitors have a useful role in helping people with LPAs (both for Property & Finance and for Health & Welfare) since people continue to find these forms unwieldy and burdensome. However, it is of concern that in our experience (with some rare exceptions) solicitors commonly insist that registration of an LPA for Health & Welfare invalidates a prior AD. They do not appear able or willing to integrate an AD with an LPA for Health & Welfare so that both become operational in the event of a person losing capacity. This is of concern because many clients we work with via ADA would like to appoint an LPA for Health & Welfare, as well as having an AD. These clients say that they want to make major decisions concerning life-prolonging treatments for themselves in advance – either
because they do not trust the people they intend to appoint as attorneys to “let them go”, or because they do not wish to burden them with this responsibility. The AD is then drawn up to cover the life-prolonging treatment decisions – and we have referred them to solicitors of their choice to draw up LPAs to cover the remaining decisions. They then often come back to us with a report that the solicitor says they cannot do this. Other ADA clients want their AD to refuse treatment for the circumstances they have anticipated in the AD but to allow an LPA to take decisions about other life-sustaining treatments if there is an unanticipated scenario in which their AD is not applicable. Again, ADA clients have not received good advice from solicitors in relation to this – in part because of the poor design of the LPA forms which militate against effective use of both an AD and LPA (see section 7).

We advise revisions to the form for Lasting Power of Attorney (Health & Welfare) to make clear if an AD is also in place and is intended to remain valid alongside the LPA.

In view of the increasing numbers of people choosing to complete both an advance decision and a Lasting Power of Attorney for Health & Welfare, we think that the relationship between the two needs to be clarified – and the co-existence of an AD also made explicit on the LPA (H&W) form.

My attorney must not override the decisions contained in my Advance Decision. She must act only in situations in which my Advance Decision is judged not valid or not applicable. I enclose with this application, my Advance Decision dated [date] but this same restriction is to apply to any future Advance Decision that I may write.”

Recommended revisions to the LPA (H&W) form:

In Section 5 of the LPA (H&W) form there are currently only two alternatives. Option A is “I give my attorneys authority to give or refuse consent to life-sustaining treatment on my behalf” and Option B is “I do not give my attorneys authority...”. At the very least an additional box is needed: Option C – “I have already made my own decisions about refusing certain life-sustaining treatments in my Advance Decision (attached) and I do not intend my attorneys to have the power to over-ride these decisions”. Then Option A could be amended to say “I give my attorneys authority to give or refuse consent to any life-sustaining treatment on my behalf which I have not already refused in my Advance Decision (attached), or under any circumstances under which my AD may be judged not valid or not applicable”.

7 We advise revisions to the form for Lasting Power of Attorney (Health & Welfare) to make clear if an AD is also in place and is intended to remain valid alongside the LPA.
The permanent vegetative state (PVS) is one of the iconic conditions which people who write ADs are often concerned about. The lay version of treatment refusal (“don’t keep me alive if I’m a vegetable”) translates into something like this in an AD:

“If I am diagnosed as being in a Permanent Vegetative State by two appropriately-qualified clinicians, I refuse all treatment aimed at prolonging my life including (but not limited to) clinically-assisted nutrition and hydration…”

We have hardly ever seen an advance decision to refuse treatment which did NOT seek to refuse treatment in the event of a permanent vegetative state. This concern reflects the origins of advance decisions in the USA where the widely-reported case of Nancy Cruzan (a 25-year-old woman who was maintained for 7 years in PVS) was directly responsible for the Patient Self Determination Act, which took effect in 1991 and gave statutory support for anticipatory decision-making\(^\text{11}\).

The Mental Capacity Act 2005 seems to give statutory support for advance decisions such that, if an AD is valid and applicable, it is legally binding on health care professionals. The medical treatments refused in the valid AD must be withheld or withdrawn at the point at which it applies to the person’s situation. There is a widespread assumption among Mental Capacity Act trainers, advisors, and more generally those responsible for implementing the Mental Capacity Act that withdrawal of artificial nutrition and hydration from a PVS/MCS patient with a valid and applicable advance decision would not require a court application.

However, there is apparently some legal uncertainty about this issue due to s. 5(a) of the Court of Protection Practice Direction 9e. It reads:

5. Cases involving any of the following decisions should be regarded as serious medical treatment for the purpose of the Rules and this practice direction, and should be brought to the court:

(a) decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state

One reading of Practice Direction 9e is that even where the patient has a valid and applicable advance decision to refuse artificial nutrition and hydration if they are in a permanent vegetative state or a minimally conscious state, the case will nonetheless need to be heard by the Court of Protection before treatment can be withdrawn. Several lawyers have informed us that they would advise CCGs/Trusts to apply to the courts before withholding/withdrawing artificial nutrition and hydration from PVS and MCS patients, even when they have an advance decision to refuse treatment in these circumstances. Since uncovering this anomaly, ADA’s work with clients seeking to avoid being maintained in PVS/MCS has

involved trying to develop a strategy for helping people write ADs which takes the possibility of a court hearing into account and manages people’s concerns about this. We want to point out in the strongest possible terms that this situation causes considerable consternation (nobody writing an AD wants to find themselves and their family embroiled in a court hearing) and creates a further deterrent and obstacle to people writing ADs. A requirement for these cases to be heard in court is also very likely to cause delays in withdrawing treatment. The delay between a best interest decision to withdraw CANH from a PVS patient and a court decision on this matter is on average around 9 months\(^{12}\) – so that this interpretation of PD9e could potentially lead to months of unwanted treatment administered to a patient who had expressly refused it in a valid and applicable AD. It could also leave doctors who do respect a valid and applicable AD – and who withdraw CANH at the point at which PVS is diagnosed – vulnerable to censure or legal action.

Our view is that s. 5(a) Practice Direction 9e is not compliant with the Mental Capacity Act 2005. We ask the Law Commission, as a matter of priority, to recommend reform of s. 5(a) Practice Direction 9e so that it is clearly compliant with the Mental Capacity Act. This could be done along the following lines (taking into account LPAs as well as ADs):

5. Cases involving any of the following decisions should be regarded as serious medical treatment for the purpose of the Rules and this practice direction, and should be brought to the court:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state (unless there is a valid and applicable advance decision refusing treatment or unless an attorney with the relevant decision-making powers authorises withdrawal)

Additionally, note that we recommend (in Section 5 above) the development of standardized statutory form which people could use to ‘opt out’ of treatment in the event that they were in the future to be diagnosed as being in a PVS/MCS.

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